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Mary M. Stanton
Perspectives on Lesbian, Gay,
Bisexual, Transgender (LGBT) Older
Adults' Decision to Disclose Their
Sexual Orientation or Gender Identity
to Healthcare and Social Service
Providers

ABSTRACT

This qualitative study explored LGBT older adults' individual decisions to disclose sexual orientation or gender identification when seeking services from health care and social service providers. Participants were recruited through local senior centers. Thirteen lesbian females and four gay males participated in qualitative interviews. All participants identified racially as white and resided in the Pioneer Valley of Western Massachusetts; ages ranged from 55 to 73 years old. Employment status varied: 35% were retired; 29% worked fulltime; 23% were disabled and 11% were semi-retired. Professions spanned business, educational, legal, media and medical fields. Thirty eight percent earned over \$90,000; 12% over \$70,000; 24% over \$21,000 and 19% under \$20,000 a year. Two participants were veterans. Seven participants were partnered, one widowed and six single. Sixty four percent owned homes and 36% rented. Religious and spiritual beliefs varied. All participants could identify at least one person as family or support.

All participants reported disclosing their sexual orientation to their primary healthcare provider and to other providers when it impacted access to services. Participants used discretion when disclosing their sexual minority status based on relevancy, safety or openness of providers. They indicated that the Pioneer Valley was a relatively safe place to disclose to providers, but that disclosure still required judgment. Many supportive providers are found through word of

mouth and participants sought different providers if they experienced homophobia.

Recommendations to increase LGBT consumers' disclosure were that providers directly ask about sexual orientation and use inclusive language in forms and conversations.

**PERSPECTIVES ON
LESBIAN, GAY, BISEXUAL, TRANSGENDER (LGBT)
OLDER ADULTS' DECISION
TO DISCLOSE THEIR SEXUAL ORIENTATION OR GENDER IDENTITY TO
HEALTH CARE AND SOCIAL SERVICE PROVIDERS**

A project based upon an independent investigation, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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2012

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At the Smith School for Social Work, we talk about making meaning of what we do; this thesis makes meaning of my brother Scott's death from AIDS over 26 years ago. I'd like to acknowledge the Shanti Project of San Francisco, the first AIDS hospice, for helping him and thousands of others with AIDS die with the dignity they deserved.

A special thank you to Betsy Bernard and Laurie Peter, MSW '91 for supporting my contribution to research on the aging LGBT community through the SAGE thesis award. I want to acknowledge and thank SAGE for the work they do to improve the quality of life for the aging LGBT community.

I sincerely thank all of my family and friends: the love we share is what gives my life the most meaning. Your love, support and belief in me got me through this thesis.

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CHAPTER I

Introduction

The purpose of this exploratory qualitative study was to examine lesbian, gay, bisexual, and transgender (LGBT) older adults' individual decisions to disclose or not disclose their sexual orientation or gender identification when seeking services from health care and social service providers.

Disclosing one's sexual orientation or gender identity is known as "coming out" as described in Appleby & Anastas (1998):

The term *coming out* originates in gay and lesbian culture. Gay or lesbian people who deliberately keep their same-gender sexual activities hidden from others as a method of stigma management are considered to be "in the closet." "Coming out," by contrast, refers to "coming out of the closet," that is, to a process in which a person decides not to continue keeping his or her activities or self-identification a secret any longer. Thus the term *coming out*, as used in the gay and lesbian community and in the gay liberation movement, has always implied some level of public declaration of one's homosexuality (p. 66).

There is little question why some LGBT individuals choose not to "come out" given the historical and present day stigma and discrimination surrounding the LGBT population. In *The Aging and Health Report: Disparities and Resilience among the Lesbian, Gay, Bisexual, and Transgender Older Adults* (2011), the authors sum up the complexity of the decision to disclose

one's sexual orientation or gender identification in the following statement:

In a world that stigmatizes LGBT individuals, disclosure, or being “out,” presents both risks and opportunities. While being out has been shown to be a positive protective factor for mental health, those who come out risk the very real possibility of rejection by friends, family members, and others as well as the possibility of losing their job and housing (Fredriksen-Goldsen, et al., 2011).

In addition to stigmatization and discrimination, LGBT people are largely invisible to the dominant heterosexual population. Due to the ageism of the United States culture, LGBT older adults may be even more invisible, even within the LGBT community. This invisibility is grounded in the presumption of heterosexuality or gender by the dominant culture. The ability of a LGBT person to pass as heterosexual or to conform to society's accepted gender portrayal of male or female contributes to this invisibility. The ageism in American society and the youth focused LGBT community can contribute to an older LGBT adult feeling isolated and cut off from a supportive community. In short, stigmatization, discrimination, homophobia, heterosexism, ageism and the ability to pass are determinative factors when associated with coming out in the older LGBT population.

Invisibility, discrimination and stigmatization have all contributed to the lack of research concerning the LGBT older adult population. Current research pertaining to the LGBT older adult population calls for more funding on state and federal levels for continued research to address the complexities of LGBT aging. The National Gay and Lesbian Taskforce published the first groundbreaking studies on LGBT aging in 2000 entitled *Outing Age*. Ten years later, the Taskforce released *Outing Age 2011* that validates the increased need for research and the continued relevancy of the findings from *Outing Age* (2001) which exposed:

...the collision of ageism, sexphobia, and homophobia that makes dignified, secure aging as a lesbian, gay, bisexual or transgender person a process fraught with obstacles. American society commonly views older adults as asexual while perceiving LGBT people as universally young and sexually rebellious. The simultaneous impact of these prejudices renders LGBT elders at best invisible and at worst expendable (Grant, Koskovich, Frazer, Bjerk & SAGE, 2009).

All these factors place LGBT older adults at greater risk for not seeking or receiving needed senior services related to healthcare, housing and social services. Current research recommendations call for legislative protection of LGBT older adults by federal and state governments and for mandated cultural competency trainings for senior service providers to ensure LGBT elder's safety and dignity (Orel, 2006). In addition, the American Medical Association warns that if physicians do not recognize patients' sexual orientation and patients do not disclose, it can result in serious medical problems (Fredriksen-Goldsen, et al., 2011).

Not all findings on LGBT older adults are disheartening. In a chapter on older LGBT adults in *Handbook of Social Work in Health and Aging* (2006), Butler disputes the stereotype that LGBT older adults are more lonely and isolated than their heterosexual counterparts based on various studies in the past decade. Butler highlights the resiliency that LGBT older adults gain in creating supportive networks of choice and in learning to cope with societal stigma and discrimination around their sexual orientation or gender identity. This resiliency benefits LGBT older adults' acceptance of the aging process. However, consistent with other researchers, Butler also points out that while LGBT older adults face the same obstacles as heterosexual elders, they face these obstacles with the added barriers to services due to discrimination. LGBT older couples also experience reduced financial security because LGBT couples do not have same

access to federal social security benefits as heterosexual couples and have to create legal documentation to protect their assets in the event that one of them becomes disabled or dies.

A 2011 Institute of Medicine study on the health of LGBT people further validates the gaps in knowledge and research on LGBT aging (IOM, 2011). In *Aging and Sexual Orientation: A 25-Year Review of the Literature* (2010), the authors concluded that a large number of articles are based on the same few studies. More research is needed to address the intersection of age cohort, culture and individual life experience on older LGBT populations (Fredriksen-Goldsen & Muraco, 2010).

The need for research is evident in the rising visibility of an increasing population of LGBT older adults, which is consistent with the growing general population of older adults. The stigmatization, discrimination and invisibility that the LGBT older adult population experiences warrants further research. According to SAGE (Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders), there are 2.9 million gay men and lesbians over 55 living in the United States (SAGE, 2010). The National Lesbian and Gay Taskforce report, *Outing Age 2010*, estimates the current American LGBT population over 65 years of age at 1.4 to 3.8 million with the potential for the population rising as high as 7.2 million by 2030 (Grant, et al., 2009). These figures rose from *Outing Age 2000* where estimates were 1 to 2.8 million in the year 2000 with a prediction of 2 to 6 million by 2030 (Cahill, South & Spade, 2001).

The issues involved in disclosing one's sexual orientation or gender identification are complex. The decision to disclose is a personal one, and many factors affect an individual's decision to come out. The purpose of this exploratory qualitative study was to gather data around LGBT older adults' decision to disclose or not disclose sexual orientation or gender identification to healthcare or social service providers.

Exploring LGBT older adults' individual decisions to disclose or not disclose offered an opportunity to gather data on:

- 1) How LGBT older adults navigated health care and social service systems;
- 2) How they assessed whether a provider may be safe or supportive of them;
- 3) What their experience with disclosure was; and,
- 4) What their recommendations to make it easier to disclose are.

Data was obtained through qualitative interviews. The findings from this study may help find ways to support LGBT older adults during the process of disclosure to their service providers. This study will hopefully add to the much needed research on LGBT aging and contribute to the overall quality of life for the LGBT elders, their allies, families, friends and communities.

CHAPTER II

Literature Review

Ruth Neustifter, in her reference to lesbian couples as an impetus for identification of cultural competencies in LGBT end of life care, reasons that further research is needed simply because the population exists (Neustifter, 2008). All members of the LGBT older adult population are worthy of adequate services and support. The LGBT older adult population is a diverse one. Kimmel, Rose and David (2006) suggest multiple reasons for further research: to increase intergenerational contact and knowledge, reduce impact of ageism and provide positive role models for transitioning into middle and old age in the LGBT community. As stated in the introduction, the current American LGBT population over 65 years of age is estimated at 1.4 to 3.8 million with the potential for the population rising as high as 7.2 million by 2030 (Grant, et al., 2009).

Rising visibility

With each census, the United States sees the number of LGBT people in America increase. The 1990 census recorded 145,130 same sex households; the 2000 Census recorded a total of 601,209 gay and lesbian families. According to a study on the 2000 U.S. Census, the count of gay and lesbian families was undercounted by as much as 62 percent (Smith and Gates, 2001). Even so, an analysis of the 2000 census found that 97 percent of U.S. counties had a senior in a same-sex partnership (Gates, 2003).

The 2010 Census was the first census to count married same sex couples. Preliminary

analysis of Census 2010 by the Williams Institute showed that 650,000 same-sex couples were counted (Gates, 2010). Still, that figure does not truly represent the entire LGBT population. The LGBT population is not accurately recorded in the census because census questions are not inclusive of sexual orientation or nonbinary gender identification. Coding errors on census forms further complicate census accuracy. The reluctance of many LGBT older adults to disclose information may further skew the accuracy of this particular population being counted.

It is important to note that data gathered by the U.S. Census Bureau is used in determining the allocation Congressional seats and the formation of legislative districts. The census data provided is used to make decisions about which community services to fund and provide, such as senior services. Each year census data drives the distribution of over \$400 billion in federal funds to local, state and tribal governments (US Census Bureau, 2011). Based on uninclusive census questions, inaccurate counts, coding errors and nondisclosure, LGBT people of all ages are not being fully considered in the monies allocated to provide much needed community services.

While Census data informs our social policy, through media, LGBT populations and their allies are starting to inform society of the presence and plight of LGBT populations. There are growing numbers of LGBT people choosing to come out to combat the ongoing issues of invisibility, stigmatization and discrimination of homophobia.

One example is the “It Gets Better” campaign. To combat isolation and suicide caused by the bullying of perceived or outed LGBT young adults, Dan Savage, a gay activist author and his husband, Terry Miller, launched the online “It Gets Better” campaign at www.itgetsbetter.org. Celebrities, politicians, athletes, organizations, professionals and everyday people “come out” as a LGBT person or as an ally to show their support of LGBT people by posting videos online to

tell LGBT youth and the general public that “it gets better.” The campaign has drawn public attention to gay teen isolation and suicide, and it has provided support and positive role models for today’s LGBT youth (Savage & Miller, 2010).

In 1998, filmmakers James Lecesne, Peggy Rajski and Randy Stone started the *Trevor Project*, the first nationwide 24 hour crisis and suicide prevention lifeline for lesbian, gay, bisexual, transgender and questioning youth. LGBT youth, educators and parents can find online support and resources for today’s LGBT youth at <http://www.thetrevorproject.org/> or by calling 866.488.7386 (Trevor Project, 2011).

Increasing support and visibility for LGBT older adults are becoming available as well. In 2010, *the National Resource Center on LGBT Aging* was created through a grant from the U.S. Administration on Aging housed within the Department of Health and Human Services. The grant was awarded to SAGE (Services and Advocacy for GLBT Elders), a national nonprofit organization that partnered with 10 other national agencies to create LGBT aging resources for senior providers, LGBT organizations and LGBT older adults at <http://www.lgbtagingcenter.org/> and to offer culture competency trainings (AOA, 2010; SAGE, 2010).

Four recent documentaries brought the plight of the struggles and triumphs of LGBT aging to the screen. In *Gen Silent*, filmmaker Stu Maddux follows six LGBT seniors as they navigate disclosure in the healthcare system as they need services (Maddux, 2009). *The Devotion Project*, a series of short films celebrating LGBT couples was created by filmmaker Antony Osso. It offers positive stories of role models for LGBT people. Osso’s first short film “More Than Ever” chronicled the relationship of an older gay male couple who were together for 54 years (Osso, 2011). The third documentary, *Sappho’s Fire*, interviewed older lesbians about the strategies, philosophies and struggles they faced as they confronted the uncertainties about

growing older (Kosmider, 2011).

The fourth film, *Edie and Thea: A Very Long Engagement*, a 2009 documentary directed by Susan Muska and Greta Olafsdottir, chronicled the relationship of an older lesbian couple who were together for 44 years. Edith “Edie” Windsor filed a lawsuit against the Defense of Marriage Act (DOMA) after Thea’s death. Because they were not able to marry, Edie had to pay \$363,000 in estate tax. All four films highlighted the experiences of people choosing to disclose or not disclose their LGBT status.

Edie's fight continues after the film. In February 2011, Edie’s lawsuit was cited in President Obama’s decision directing the Justice Department to stop defending the DOMA law that bars federal recognition of gay marriages. On June 6, 2012, U.S. District Court Judge Barbara Jones ruled the Defense of Marriage Act is unconstitutional in the Edith Windsor case, brought by the ACLU, and has directed the government to pay her back for the estate taxes she was forced to pay (Geidner, 2012).

Historical context and coming out

So while LGBT older adults are becoming more visible, they still contend with stigmatization and discrimination due to their sexual orientation or gender identification and, to some degree, internalized homophobia. Older individuals’ historical experience of stigmatization, discrimination and internalized homophobia may be factors in determining whether they consider it is safe or not to disclose their sexual orientation to healthcare or social service providers.

Research data has begun to specify some of the negative experiences identified by older LGBT adults. *The Aging and Health Report* study (2011) found 82% of their LGBT older adult participants were victimized at least once due to their perceived sexual orientation or gender

identity; 64% were victimized three or more times. Participants encountered discrimination in employment and housing; and one in ten surveyed reported being denied healthcare or provided with inferior care due to their perceived sexual orientation or gender identity (Fredriksen-Goldsen, et al. 2011).

The historical time period in which older LGBT individuals discovered that their sexual orientation or gender identification was different than heterosexual also may influence their decision to disclose. The *Outing Age 2010* report clearly describes the negative psychosocial experiences of current LGBT elders:

LGBT older adults who came of age before the gay liberation movement of the 1970s have lived largely in the context of extremely hostile social, medical and mental health systems, making self-advocacy within aging services agencies or institutional settings overwhelmingly difficult for many of these elders (Grant, Koskovish, Frazer, Bjerk & SAGE, 2009).

The 2011 *Public Policy & Aging Report*, published by National Academy on an Aging Society, discusses resilience and disparities, framing the question of coming out in social and historical contexts:

Many lesbian, gay, bisexual and transgender older adults have spent the majority of their lives masking their sexual orientation and gender identity, with their life stories largely silenced. Unlike some minority groups, most lesbian, gay, bisexual, and transgender older adults are not readily identifiable and they must constantly manage the disclosure of their sexual orientation or gender identity fearing discrimination and victimization (Hudson, 2011).

There are many historical examples of inequities of treatment in healthcare care due to

race, socioeconomic status, sexual orientation, gender, ethnicity and age. The medical human experimentation against Jewish people, which included homosexuals, was exposed in the 1945-46 Nuremberg trials in Germany and the U.S. government's withholding the cure for Syphilis to rural African American men in the 1932-72 Tuskegee Syphilis Study are two examples of unethical practices. Both examples involved unethical healthcare professionals exploiting underrepresented and vulnerable populations (Otis-Green and Rutland, 2004) that have suffered from stigmatization and discrimination.

The current aging LGBT cohort witnessed and/or experienced the overt stigmatization and discrimination toward homosexual males at the advent of and during the AIDS Epidemic. The sentiment among the lesbian and gay community at that time was expressed by the author of a 1988 book on the AIDS epidemic. In *And the Band Played On*, Randy Shilts wrote:

The bitter truth was that AIDS did not just happen to America – it was allowed to happen by an array of institutions, all of which failed to perform their appropriate tasks to safeguard the public health. This failure of the systems leaves a legacy of unnecessary suffering that will haunt the Western world for decades to come (Shilts, 1988, p. xxii).

There are also different age cohorts within the LGBT older adult population and their different experiences may impact their decision to disclose. The oldest age cohort (75 years old or older) grew up pre-WWII, during the depression and before the words lesbian or gay were spoken outloud. This cohort is most likely to have hidden their identity and experienced or witnessed the loss of family and/or career; they feared hospitalization or arrest if their sexual orientation or gender identification was perceived or discovered. The middle age cohort of LGBT elders (65-75 years old) grew up post WWII, during the civil rights movement and the

beginning of the gay rights movement. Both cohorts created communities in secret and even used false names for safety and lived in fear of being found out (Maddux, 2011). The younger cohort of older LGBT adults (55-64 years old) came of age during or after the Stonewall Riots of 1969 and are most likely to be open about their sexual orientation but still witnessed or experienced institutionalized discrimination (Kimmel, Rose, & David, 2006).

Other factors may influence an older adults' ability to disclose to a healthcare or social service provider including: when they came out, where they came out, what age they came out or what happened when they came out. For example, a 64 year old lesbian who came out at 25 years old and has managed being out for 39 years may feel more comfortable with disclosure than a 64 year old lesbian who was heterosexual and married for 30 years and came out at 62. Or perhaps the 64 year old who came out at 62 is more comfortable because she hasn't had to face the stigma of being out for 39 years and feels secure in disclosing. People come out at all different ages and that can affect their decision or ability to disclose (Taylor, 1999). Cultural factors may influence the willingness to self-identify as gay. An LGBT older adult's ability to disclose may be affected by other cultural identities such as ethnicity or socioeconomics (Rust, 1996).

Over the past 40 years, there have been many different models of the stages of homosexual identification (Brady & Busse 1994; Cass, 1979; Kus, 1985; McCarn and Fassinger, 1996; Troiden, 1988). All models represent different stages or phases of realizing one's homosexuality, whether developmental or linear or phase oriented, and all included the coming out process as something that an individual does at some point in learning to integrate their homosexual identity into their whole identity. Balsam & D'Augelli (2006) proposes that the process of coming out and identifying as an LGBT person involves significant personal growth and self-awareness, which can increase the internal resources that promote resiliency.

A 1992 in-depth interview study suggested a 2-phase with 33 lesbians (aged 18-68 yrs). One phase was identified as personal risking where the lesbian determined her physical and/or psychological safety before moving into the second phase of risking self-disclosure. The data from the study found that lesbians are uncomfortable in many health care situations and indicated that more welcoming provider responses would improve their comfort and increase their utilization of healthcare. The study also identified six other themes that the sample reported pertaining to healthcare: 1) they avoided traditional health care system, except for mental health services, 2) they relied on alternative health care providers, partners, friends and self for holistic care, 3) they delayed healthcare, 4) they didn't disclose to healthcare providers, 5) they sought out lesbian or other female providers when available and 6) they sought and used substance abuse and mental health services, programs or support groups (Hitchcock & Wilson, 1992).

Empirical research

The invisibility, stigmatization and discrimination LGBT older adults have experienced places them at greater risk of not seeking or receiving needed senior services related to healthcare, housing and social services. Research on LGBT older adults recommends legislative protection of LGBT older adults by federal and state governments and mandated cultural competency education for senior service providers to ensure LGBT elders' safety and dignity. In addition, the American Medical Association warns that if physicians do not recognize patients' sexual orientation and patients do not disclose, it can result in serious medical problems (Fredriksen-Goldsen, et al., 2011).

A 2011 Institute of Medicine study on the health of LGBT people further validates the gaps in knowledge and research on LGBT aging and highlights the need for cultural competency education for healthcare and social service providers (IOM, 2011). A 2010 study of 132 medical educational institutions highlighted the gap in cultural competency within the medical

profession. One finding of the study revealed that undergraduate medical education institutions reported a median of 5 hours of LGBT content with inconsistent coverage of the health care needs and health disparities of the LGBT population. While physicians are instructed to ask a patient if they are having sex with males or females, there is no instruction on further questioning (Obedin-Maliver, et al., 2011).

In the *Handbook of Social Work in Health and Aging*, Butler (2006), pulled together practice guidelines for working with LGBT older adults from earlier researchers. Below is a summary of Butler's guidelines in working with LGBT older adults:

..recognize and work on your own heterosexism and homophobia; recognize diversity among the LGBT community; protect privacy and confidentiality; listen and connect with the older LGBT adult; don't generalize problems attributing it to age or sexual orientation; honor and include their relationships; assess your agency's actions and policies and advocate for change; utilize inclusive language; educate yourself about special issues in GLBT aging; find and refer respectful service providers; assist the LGBT older adult in connecting with community support; develop GLBT-friendly resources, include GLBT older adults in planning and advocate for change in social policy (Butler, 2006).

The question of whether LGBT people come out to healthcare providers or social service providers has been studied since the late 70s. In 1980, Dardick & Grady conducted groundbreaking research about the openness between gay persons and their healthcare professionals. In their survey of 622 men and women, recruited through an ad in *Gay Community News*, 49% indicated that they disclosed their sexual orientation to their physician, 11% assumed their health provider knew and 7% said they would disclose their sexual orientation to their health provider under any circumstances and 27% felt that health professionals they had in the past were

prejudiced. Respondents indicated that professionals' attitudes toward homosexuals made a difference in diagnosis and treatment. The study found that coming out to providers was associated with more satisfaction.

An article by Johnson and Guenther (1987) discussed why a lesbian may want to come out to her physician and why her physician should care if she did. From a psychological perspective, "lesbian patients who have serious or chronic illness require the support and care of their partner and/or close friends. The involvement of these individuals is best facilitated if they are directly included the decision-making and therapeutic process" (Johnson & Guenther, 1987).

Johnson and Guenther conclude that the political implications of LGBT older adults coming out are simple: if they come out to their physicians, the more attitudes will have to change. If LGBT people don't come out, physicians or other providers will think they do not treat LGBT people and therefore don't have to consider the issue (Denneny, 1981; Johnson & Guenther, 1987).

More recently *The Aging and Health Report* researchers found that "more than one-fifth (21%) of a sample of 2,500 LGBT older adults had not revealed their sexual orientation to their primary physician, and bisexual older women and men are less likely to disclose than lesbian and gay older adults" (Fredriksen-Goldsen, et al., 2011). Based on *The Aging and Health Report*, not coming out can lead to sub-optimal treatment.

The literature reviewed for this study, including both policy statements and empirical investigations, suggests that coming out to providers on the part of older LGBT individuals is multi-determined. This study was designed to obtain narrative data from a sample of the older LGBT population, thereby contributing their "own voice" to existing literature about this phenomenon.

CHAPTER III

Methodology

Project purpose and design

The purpose of this qualitative study was to explore LGBT older adults' decision to come out in relation to seeking help from health care and social service providers. Findings were obtained through individual interviews with LGBT older adults and were examined for associations among demographic data and for associations between demographic data and thematic findings in the qualitative data.

Sampling

A non-probability sampling method of convenience was used to obtain the sample size of 17 participants for this study. The study population was LGBT older adults over 55 years of age. The sampling frame for participation consisted of LGBT older adults who participated in senior centers in the following Western Massachusetts town: Amherst, Easthampton, Hadley and Northampton. Through this convenience sampling, the researcher hoped to draw participants with a varying range of demographics. Response to initial recruitment was slow and word of mouth from initial interview participants proved to be a better method to reach the remaining participants for the study.

Recruitment process

An invitation to participate in this study was distributed through four Western Massachusetts senior centers in Amherst, Easthampton, Hadley and Northampton. The directors of the senior centers were contacted by telephone to introduce the study and obtain approval and agreement to post the study recruitment flyers (Appendix A) on the community bulletin board at the senior centers.

After a director agreed to post the study recruitment flyer, a confirmation letter (Appendix B) was sent by email with the study recruitment flyer to be posted. In addition, the director of the SAGE (Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders) Western Massachusetts' chapter distributed the study recruitment flyers by email and at the monthly meetings for LGBT and their allies at two of the above senior centers. Potential participants were able to contact the researcher through the contact information listed on the study recruitment flyer.

Characteristics of the participants

Study participants were 55 to 73 years old, understood English and identified as either lesbian or gay. No bisexual or transgendered individuals responded to the study. Participants indicated that they understood and accepted that their participation was voluntary and that no payment or compensation would be given for participating in this study. Before acceptance into the study, at the point when potential participants contacted the researcher, they were asked to identify their sexual orientation or gender identification and age; if they did not meet these inclusion criteria, they were thanked for their interest in participating in the study and not interviewed. Once participants had been identified as meeting the above criteria, an interview was scheduled. All participants read and signed an informed consent form (Appendix C) before an interview began.

Instrumentation

Qualitative interviews were conducted in person or by telephone. Interviews were recorded to accurately capture answers. Participants consented to recording of the interview. The interviews were approximately thirty minutes to one hour long. Screening questions related to age, sexual orientation and gender identification were asked in the initial inquiry to establish

that participants met the eligibility criteria. The interviewer asked demographic questions first; these were followed by open ended questions relating to participants' decision to disclose or not disclose their sexual orientation or gender identification with healthcare providers or social service providers.

Participants were asked questions in the following demographic areas: age; disability status; ethnicity/race; gender identification; educational background; employment status; family/support system; age of gay identification; geographic location; household income; housing arrangement; profession; relationship status; religious or spiritual affiliation; sexual orientation and veteran status. The demographic questions were followed by open ended questions related to decisions and experiences in coming out to healthcare and social services providers (Appendix D). The interviews began after Human Subject Review Committee approval on March 14, 2012 (Appendix E). Interviews were conducted until a total of 17 participants were interviewed.

Protection of human rights

This exploratory qualitative study was approved by the Smith College School for Social Work Human Subjects Review Committee before it began. Participants with questions or concerns about their rights or this study were provided with the researcher's and the Chair of the Smith College School Social Work Human Subjects Review Committee contact information.

This study methodology approval by the Smith College School for Social Work Human Subjects Review Committee assured study participants that minimal risk from participation was anticipated. A list of LGBT older adult supportive resources were listed on the bottom of the second page of the informed consent form (Appendix C). Study participants received the informed consent form to read and sign to indicate consent to participate before each interview

was conducted.

Assurance of confidentiality and security was provided in the informed consent form (Appendix C). A confidentiality agreement (Appendix F) for a transcriber of interviews was created for and approved by the Smith College School for Social Work Human Subjects Review Committee. However, all recordings were transcribed and heard only by this researcher. Research advisors had access to data obtained from recordings, but not to identifying information about the participants. In accordance with federal guidelines, data will remain securely stored for a period of three years; after this period, the data will be destroyed or continue to be maintained securely. Data is discussed in the aggregate to protect the confidentiality of the participants. Any interview excerpts quoted in the findings are carefully disguised to remove any potentially identifying information.

Benefits of participation

Participants in this study provided information that has been compiled on LGBT older adults' decisions to disclose or not disclose their sexual orientation or gender identification with healthcare providers and social service providers. The data gathered provides insight into what may best assist LGBT older adults around the decision to come out or not. The data collected from this study may be useful for further research in areas that lack data and bring attention to the challenges of LGBT older adults' decision to disclose or not disclose their sexual orientation or gender identification to healthcare providers and social service providers.

Limitations to the study

Limited response to recruitment methods affected the amount of data that was collected. The overall individuality and diversity within the LGBT older adult population makes it difficult to generalize from the interview data to the overall experience of an average LGBT older adult's

decision to disclose sexual orientation or gender identification. No bisexual or transgendered persons responded to the call for participation in the study. The researcher's own personal bias from being a lesbian approaching midlife was an important limitation to consider. However, the researcher made every effort to remain unbiased and to report the study findings objectively. Finally, there could be a limitation because of the geographic area and the locations of recruitment. Due to the gay friendly reputation of the Pioneer Valley of Western Massachusetts, there may be more than usual LGBT self-disclosure. There also may be a self-selection factor involved because recruitment was confined to LGBT older adults who participate in the senior centers or in SAGE of Western Massachusetts.

CHAPTER IV

Findings

The purpose of this exploratory qualitative study was to examine lesbian, gay, bisexual, and transgendered (LGBT) older adults' individual decisions to disclose or not disclose their sexual orientation or gender identification when seeking services from health care and social service providers. The data from this study has the potential to support future research as well as contribute to social policy and cultural competency regarding services and care provided to LGBT older adults. This chapter presents and summarizes the findings of 17 interviews with 13 lesbian female and 4 gay male participants.

No transgendered persons were interviewed in this study. While no participant answered that they felt they were a different sex than their sex assigned at birth, four lesbian participants discussed issues of gender nonconformity such as acting or being seen as a "tomboy" during their adolescent years. One participant commented on the experience of trying on her father's clothes at the age of four and her family acknowledging when she came out that they knew since then that she was different. Three lesbian participants discussed being comfortable with dressing or expressing socially defined masculine behaviors.

No bisexual participants were interviewed, though four participants said they identified their sexual orientation based on their current homosexual relationship and that it may be different if they were single.

Demographics

Age, sexual orientation, gender and race

Participants were asked 16 demographic questions and six open ended questions. Thirteen lesbian females and four gay males were interviewed. Participants' ages ranged from 55 to 73 years; they were born between the years of 1939 and 1957 with the median age being 63.1 years old. All participants self-identified as White or Caucasian.

Education, employment status, professional experience and income range

Eighty two percent of participants had the equivalent of a Masters degree or higher. Twenty nine percent of participants considered themselves living with a disability. Employment status varied among participants: 35% were retired; 29% worked fulltime; 23% were disabled and 11% were semi-retired. Out of the participants who worked fulltime or were semi-retired, 71% of them were self-employed or ran their own business.

Careers spanned business, counseling, education, legal, media and medical professions. Most participants reported having two or more professions throughout their professional life. Participants reported working in educational professions as teachers and administrators at all levels from elementary school through postgraduate study. The clinical, counseling and medical professions were well represented with participants working as social workers, counselors, lab technicians, life coaches, nurses and medical transcribers. In the media professions, participants worked as authors and TV and radio specialists. The business and legal and nonprofit professions included lawyers, fundraisers, administrators and administrative support occupations. Two out of the 17 participants were veterans and had served in the United States Armed forces.

Participants' incomes ranged from over \$90,000 to under \$20,000 a year. Thirty eight percent of participants currently earned over \$90,000; 12% between \$70,000 and \$89,000; 24%

between \$21,000 and \$69,000 and 19% under \$20,000 a year.

Relationship status, geographic location, housing and support system

Five participants described themselves as married and living with their spouse with one participant identifying as widowed. Six participants were single and all but one of them lived alone. Three participants described themselves as partnered and living with their partner and two participants described themselves as in a relationship and living alone.

Participants were from Amherst, Easthampton, Goshen, Leverett, Northampton and Springfield. The largest concentration of participants came from Northampton at 41% and Easthampton at 24 percent. Sixty four percent of participants owned a house or condominium; 18% of participants rented an apartment and 18% lived in government-subsidized housing.

Responses varied when participants were asked about whom they considered their family or support network. All participants could identify at least one person or organization they considered within their support network. The main supports described by participants included friends, ex-partners, neighbors, as well as family of origin including mothers, fathers, brothers, sisters, nieces, nephews, sons, daughters, stepchildren and in-laws. All couples, regardless of labeled relationship status (married or partnered), identified their significant other as their family or major support. Forty seven percent of participants had children or stepchildren. Participants also identified support systems such as SAGE, social services organizations, business or social networks and 12 step support groups.

Religion and spirituality

Religious affiliation varied among participants. Forty seven percent of participants described themselves as spiritual versus or in addition to following an organized religion. A common response regarding spiritual versus religious affiliation:

- “I consider myself spiritual but not religious.”
- “I don’t follow an organized religion.”
- “I draw from different beliefs, kind of more eclectic.”

The religious or spiritual preferences mentioned by participants included: Agnosticism, Buddhism, Catholicism, Christianity, Congregational, Course in Miracles, Eclecticism, Jewish, Native American, Nature, Pantheism, Protestant, Quaker, Spiritualism and Unitarian Universalism.

Coming Out Experiences

Age of sexual orientation realization

Participants were asked what age they realized their sexual orientation was different than heterosexual. Participants reported realizing this as early as four years old up to 44 years of age. Two participants reported they had earlier experiences with the same sex but denied their sexual orientation to others as well as to themselves until their thirties or forties. One participant said “I knew I was different but there just wasn’t a word for it where I came from.” Another participant said, “I got called a lesbian but I didn’t even know what it was.” Another participant said, “My family knew I was different before I did.”

Four participants went to same sex only schools; two of the participants felt that sexual orientation wasn’t an issue because of the same sex environment. Others felt it wasn’t necessary to label their feelings or actions as described by one participant, “...having encounters with people before I put a name to it, seemed perfectly natural to me so it didn't seem to me [at the time] to need a label...” Another participant who went to a same sex catholic high school said, “We didn't talk about, it’s just the way we lived... [there was] no shame or secrecy, [we] just knew that we were a close knit group...”

First same-sex romantic feelings

Participants were asked when they first experienced same sex romantic feelings. Participants reported having innocent crushes on teachers or classmates of the same sex as early as first grade, but did not act on feelings until late adolescence or from early to middle adult years. The majority of participants experienced and acted on same sex attractions between the ages of 12 and 30 years. Many participants described coming out as a gradual process as reflected in one participant's response, "being open and honest with myself at 30...identifying as bisexual or gay and then committing to labeling myself as gay at 35..." Other participants reported denying their sexual orientation to themselves and others with one participant responding, "I simply blocked it out and then I didn't."

Nine of the participants reported being in a heterosexual marriage before coming out. The typical comments pertaining to being married before coming out were:

- "It was what you did."
- "It seemed the right thing to do."
- "It was what was expected...I just wasn't aware there was another option..."
- "In my neighborhood ...or family...growing up, you were a nurse, a teacher, you got married and had a family and those were the options..."

First coming out experiences

Participants reported coming out to another individual for the first time between the age of 12 to 44 years. Participants acknowledged their LGBT status for the first time to many different people in many different circumstances. The variety of people were: the first person they had a same sex relationship with; their friends; former spouses; family members such as: a parent; a sibling, an aunt or uncle; their children; or a healthcare provider; a therapist or their

professional colleagues.

Participants chose to come out for the first time in letters or conversations or simply if they were asked. Reactions to participants coming out varied as much as the people they came out to. Responses ranged from people accepting disclosure or saying they already assumed, denying the disclosure or rejecting the participant. More than a third of participants experienced some form of estrangement after disclosure. Reparation of these relationships has occurred for some, but not all.

One participant described coming out to his parents and being surprised that his father was supportive and that it brought them closer. Another participant said, “[my] first time, I was confronted in therapy...therapist said ‘you are in love with x that makes you gay’ and I said no it makes me in love with x.” One participant reported never disclosing her sexual orientation, stating, “Last year [came out]... I don’t know, I didn’t acknowledge it for a long time and I don’t ever remember telling anybody, they found out but not from me.” Some participants expressed feeling relief in coming out, as reflected in this participant’s response when asked about if he discloses his sexual orientation, “Yes, I am out to everybody. Having kept it a secret for so many years ...having that not be so good for me...it was a relief.”

Circumstances of coming out to a person for the first time ranged from one participant coming out to her colleagues at a convention and having it turning into her “coming out” party to other participants’ families’ reactions of immediate or gradual acceptance or to being disowned. One participant’s response intensely described the loss she sustained in coming out:

“I wasn't prepared for the amount of loss I sustained. It took its toll. I felt a lot of internalized homophobia. I really blamed the people and systems and the institutions for a long time, it's only been within the last 5 years... that I found people that I've really feel

loved by...”

Participants’ described varied, but similar experiences around their first time coming out. One universal theme was that participants expressed the awareness of the discrimination and stigma that their sexual orientation comes with and the potential for emotional and physical risk in disclosing sexual orientation. Participants recognized that not every lesbian, gay, bisexual and transgender older adults felt the freedom to disclose. One participant's response summed up what many participants expressed:

“Well I think that there are lots and lots of people who are economically vulnerable in a way that I am not and so that I am sure that even here in the ‘happy valley’ that you might be afraid for your employer or landlord to know or that if you tell one healthcare provider that they will tell someone else.”

Another participant talked about fitting into the “norm” of society and said, “...I imagine if someone chooses to dress him or herself in a more in your face kind of way, he/she might find it more important or more difficult [to disclose] that they were gay or homosexual.” It was clear by participant responses that disclosure had the potential for exposure to emotional and physical vulnerability and the decision to disclose or not disclose had the potential to help participants manage and protect themselves from this vulnerability.

Factors and experiences that influenced disclosure to healthcare or social service providers

All participants reported at least one experience of disclosing their sexual orientation to a healthcare or social service provider. All felt it was important to disclose their sexual orientation to at least their primary care providers. All participants said that they would not hide their sexual orientation if a provider directly asked them or if they felt their sexual orientation was relevant to the services they were seeking.

However, all but three participants expressed that they don't always disclose their sexual orientation to providers because they don't think it's always relevant. Common examples of providers who were seen as irrelevant to disclose to included the following: dentists, dermatologists, eye doctors and podiatrists. One participant's response reflects what other participants described around the decision to disclose: "For the most part, I don't hide it...sometimes it is not terribly relevant, which is not being disrespectful of my sexual orientation. For example, I don't know if it's necessary for the eye doctor to know." However, one participant, who believed it was important to be out to all providers, said:

"Yes it's an absolute, that's usually the first thing I tell them. It's not in my best interest to not tell them for a couple of reasons. If they have a problem, I don't want to go to them...secondly, there are issues that are likely to come up with a gay person that might be different than a straight person. If there is something, I think it is really important for them [the provider] to know..."

All of the participants felt it was important to disclose for the basic reason of finding out if the provider is gay friendly or tolerant. Gauging a provider's response was commonly given as a reason to disclose. As one participant said when asked if she felt it was important to disclose: "Yes, it's important to me because I want to see how they respond, I want to figure it out [whether they are okay with my sexual orientation.]"

Everyone expressed that deciding whether to disclose their sexual orientation was akin to taking the temperature of the situation. Participants responded:

- "Sometimes I think twice, sometimes I like to feel out the situation before I disclose..."
- "I don't mention it [sexual orientation] unless it comes up in a talk..."

- “If I feel an easy flow of conversation...there is no reason to edit what I am thinking if that person is apparently friendly...”
- “You stop yourself when a person is hostile for any reason...”
- “I take the temperature of the room...does it feel okay to come out.”

Participants were also reflective of the not-so-distance past when it was perceived as more dangerous to come out. One gay male talked about feeling vulnerable but still chose to disclose. He said:

“I lived through the AIDS crisis...therapists were locking their file cabinets because they thought the government was going to come in. I've been through the worst of the worst in that situation so if somebody knows, I have no problem anymore but we all are very vulnerable.”

A lesbian participant referred to the historical treatment of homosexuals when asked about whether she was concerned with her disclosure being documented:

“Depends on the mood I'm in, I could see things change quickly, I can see the 1930s and 40s of Germany happening anywhere. Hopefully we have enough fortitude in this country, enough sense of history to remember. I try not to focus on it...not a whole lot I can do about it. I try to be super aware and make my own special corner of the world safe or move to a place [Pioneer Valley] like here.”

Other participants acknowledged that they don't come out, but they don't hide it. One participant expressed the ambivalence of disclosing:

“I don't really come out but I don't hide it either, I let them make their own assumptions about a woman who is alone...I let people assume whatever they want to assume but I've never hidden my sexuality. But I don't come right out and say I'm gay, I don't see any

purpose in that...”

Another participant responded:

“I have never been in the closet, I don't go around parading it to everybody but I made a promise to myself if anyone ever asked I would never lie unless my life was in danger, if someone was going to beat me up, but I don't see myself as being in the closet. I've never had any problems coming out.”

Separate from disclosing to healthcare or social service providers, participants spoke of times in their professional lives when coming out might risk losing their jobs. Common responses about past experiences were:

- “My counselor recommending that I not come out at my school...that I would have been a target...I didn't lie...I would answer that I wasn't married or I was single...”
- “Part of it [not being out] was connected to a corporate career. Women I knew that were working in different corporate jobs at the time that invented men and would ask a gay male friend to accompany them to a company party. I didn't do that and I am not putting that person down, it was part of their survival skills...I was not out but I wasn't totally closeted. I wasn't talking about the person I was with as my partner, but as my friend...”
- “Everybody knew...but no one talked about it.”
- “I would have lost my job...my partner did.”
- “I would have been dishonorably discharged from the military.”

Participants also described being able to eventually come out over the span of the last 10, 20 or 30 years. Many participants expressed that as they aged, they were not as concerned with a provider finding out their sexual orientation. One participant said, “When I retired there was no

need to couch anything in anything.” Another response was: “For a number of years I was confused about doing it...I’m pretty, pardon the pun, “straightforward...I never hide who I am anymore.” Participants reported positive experiences of disclosing:

- “No negative experiences. If I felt there was any kind of homophobia I would leave.”
- “People have been supportive in this area.”
- “Never had a healthcare provider with a negative reaction. If I had one I wouldn’t go back.”
- “All been supportive, I present it in such a matter of fact way that nobody has raised an eyebrow.”
- “Nothing negative at best positive at worst neutral. It’s been kind of a matter of fact.”

Participants also reported negative experiences. Four lesbian participants reported negative experiences that limited their access to gynecological care. One participant reported that even after ten years of being out to her gynecologist, her gynecologist continued to ask her how her sexual relations with men were until she finally told her that unless she acknowledged her lesbian orientation, she would go elsewhere for care. The participant reported the gynecologist no longer asked the question, but the gynecologist’s response was cold. Another lesbian participant reported that disclosure of her sexual orientation was removed from her medical record and when she asked to have it corrected she was given a hard time by the provider’s staff because they [the provider] felt it wasn’t important or pertinent information for the medical visit. The participant said,

"They [the provider] made that decision for me and that's discriminatory. When they asked why it is important? I said I don't go anywhere without people knowing exactly who I am.

It matters to the whole community and I'm willing to stand up to the plate. They [the provider] don't understand the health issues of being part of a minority. "

Two other lesbian participants reported that they felt physically violated by a gynecologist after the tone of their visit changed upon disclosure of their sexual orientation. One incident occurred in a clinic started by two lesbians and that participant was shocked that it occurred there. The other lesbian participant has not been to a gynecologist since.

One lesbian participant described an interaction that she thought occurred commonly with healthcare providers. During an emergency room visit, a provider insisted she answer a question about birth control. When the participant responded there was no possibility that she was pregnant, the provider still insisted that she answer the question; the participant responded "lesbianism." The participant reported that her comment ended the provider's insistence, but it was infuriating.

Almost all lesbians felt it was important to come out to their gynecologist as indicated in one response: "I don't come out to my dentist; I don't think it's important but I think it's important to come out to my gynecologist."

During the process of each individual interview, all participants said that if they came across a healthcare provider that was homophobic, they would look for a different provider. One participant answered,

"If my doctor was clearly homophobic and not treating me with respect, I would not trust him as a professional and would want someone different even if they were an expert in their field. I'm not sure they could give me their best care if they can't respect me as an individual..."

Another participant echoed the sentiments of all participants, and stated, "If I felt there was

any kind of homophobia, I would leave."

All coupled participants said the factor that influenced their decision to disclose their sexual orientation was when they or their partner were seeking emergency healthcare services or when jointly going to healthcare provider appointments or applying for housing. Participants in a coupled relationship reported mostly positive experiences with their providers, but described instances where they had to emphasize that they were in a same sex relationship or that they were the healthcare proxy for their significant other. One participant explained:

"I don't make a point of it but I make sure they know my partner is my partner and my healthcare proxy. Only once have I had a problem with a healthcare provider. A foreign born healthcare provider insisted on directing questions to my partner who was out of it. I told her I could answer that question...the doctor said 'And who are you?' I said I am her lifetime partner...the doctor again turned to my almost comatose partner and asked another question and I again said I can answer...She said, 'What is your relationship to this person?' I was absolutely beside myself, here my spouse is almost dead and she didn't get it, she came from a culture that couldn't hear what was being said."

One coupled participant referred to disclosing as a matter of routine when providers asked about marital status. Another participant said: "Yes, I come out to healthcare providers as soon as they ask if I'm single or married and who is my emergency contact." When she was asked if she would still disclose if she were single, her response was, "I would not volunteer it if it was not related to my medical care. I don't know many single heterosexuals that say I'm heterosexual."

One participant indicated that she includes her partner in her disclosure as exemplified by the following comment:

“If it seems like it is important for them to know, I come out. Providers like my dentist, I don't come out explicitly but I think he probably knows, I haven't explicitly come out to my dermatologist but if he asked or needed to know for some reason, I would tell him.

But very often it will come up casually in conversation. I might say ‘my partner does’...”

Another participant reported that she is more likely to disclose her sexual orientation if it is related to sexuality or if disclosure would ensure access for her wife to be a part of the medical decision-making. She also added that she might disclose if she felt it would help in the development of a relationship with a provider or make it clear who she considers to be her family.

In contrast, another participant described an incident where she did not disclose her sexual orientation when applying for housing because her partner was closeted. She said it was a very distressful situation for her not to disclose their relationship but that everyone was fine when they found out.

Two veterans that were interviewed indicated that they did not disclose their sexual orientation in the past because during their military service such a disclosure would have earned them a dishonorable discharge. The repeal of “Don’t Ask Don’t Tell,” the 1993 military policy that prohibited military personnel from asking about sexual orientation and prohibited anyone who was openly homosexual from serving in the military, was a relief to one participant who felt she would now be more likely to disclose. She explained,

“I don’t have as much of a problem [to disclose] now as I used to, I was scared because I got most of my healthcare at the VA [Veteran’s Administration]. I was concerned I would lose my healthcare. I wasn’t concerned about how they would treat me, just thought I would lose my healthcare. Same with another friend of mine, nobody knows

how they would have reacted.”

Finally, it is noteworthy that this study was conducted in the Pioneer Valley of Western Massachusetts. Participants indicated that living in the gay friendly Pioneer Valley was one of the key reasons they felt comfortable enough to disclose their sexual orientation to providers. Three of the seventeen participants, who had grown up in the Pioneer Valley but moved away and returned for family reasons, expressed that the tolerance towards homosexuals was a positive factor for returning to the area. However, one of these participants also expressed feeling hurt when running into old friends who were tolerant, but distant, because of her sexual orientation.

Fourteen of the participants included other reasons for moving to the Pioneer Valley such as educational or professional opportunities or for a relationship. Regardless of why a participant decided to move to the Pioneer Valley, participants were pleased that they moved to the area because of the tolerance and acceptance of homosexuals and because of the large lesbian and gay community.

Participants have found providers in the Pioneer Valley easy to disclose to because of providers’ positive or non-surprised reactions to their disclosure and, because of inclusive language on intake forms. Some have providers who are out professionally or who are identified in the community as gay or lesbian. Every participant responded that, for the most part, they have found tolerant providers or avoided non-tolerant providers through word of mouth referrals.

One lesbian commented on the gay friendly history of the area and the legality of gay marriage in Massachusetts as being reasons why it may be easier to disclose. She said, “...it’s changed for the better with gay marriage and with the history that it’s okay to be gay here, more people are more on target [gay awareness]...once in a while people just don’t automatically include you [sexual orientation] in their world view but when you remind them, they say ‘oh

yeah'..." Another participant commented he'd never had a negative experience and said:

"I've never had a healthcare provider with a negative reaction. If I had one, I wouldn't go back. In this area there are plenty of healthcare providers who are gay or gay-supportive and positive. I came to Northampton because it's a supportive community. It never occurred to me that it would be an issue. Maybe somewhere else...If I moved someplace else, I'd be sure to find a good doctor before I moved."

All participants stated that they would seek a different provider if they experienced homophobia. However, a participant said if she encountered an expert/specialist who was homophobic, she would try to have a conversation with the provider to see if it was possible to work with him or her before seeking another provider.

All participants indicated that they felt relatively safe to disclose their sexual orientation. However, if they sized up a situation where they felt they would not be safe to disclose, they might not. The following responses indicate the reflective process and judgment that is used to determine where/when it's safe to disclose. One gay man commented, "If I lived in one of those [homophobic] places, out of my own sense of preservation I may change my approach but I've never had to, I've always lived in major cities. Within those cities they were pretty tolerant." Another participant stated, "What my fear is – if my spouse...predeceases me, I wonder, I have [relatives] that live in a red state, I would never live south of the Mason Dixon line." Another participant discussed her hesitation if she and her partner were not in the New England area:

"I don't know how I would feel if we were traveling, say to New Orleans or Texas or other states, I don't know if I would be as open, I would certainly make it clear that this is my friend and that I'm her health proxy, whether I would say 'this is my partner'..."

Participants experienced providers who recommended other gay friendly providers or

discreetly cautioned them about not-so-gay-friendly providers. A veteran participant described her interaction when a VA physician who happened to be a lesbian saw her:

“She [the physician] said, 'I know but I am not going to put it in your record because I'm not sure how they are going to react. I will treat you accordingly but I don't think we have to put it in here [medical record].' But that was before the rescinding of the Don't Ask Don't Tell.”

When recommending a provider that was gay, most providers do not directly disclose that the provider is gay. When one participant asked her provider for a referral to a psychotherapist, she said, “...The provider suggested someone who he said was ‘very very gay friendly’ so in other words... that was his way of saying that the guy was gay, people are still protective about outing people.” No participants directly indicated that they chose a provider because the provider was gay, but at least 4 of the lesbian participants indicated that they preferred female providers and one male participant said it was important that his provider be knowledgeable in gay male health. One lesbian participant discussed having a lesbian provider who talked about her family which made her feel more comfortable and that she could talk about being a lesbian if she wanted to. A gay male participant talked about the fact that his social network includes gay providers and how that contributes to not really giving any thought or hesitation when coming out or “being out.”

Some participants said that even if a provider was homophobic, they would not hide their sexuality. One participant said:

“Never found it [disclosing] to be a problem, I know that there are people out there that hate us and think that we should go to hell but you know, I don't think I would hide my sexuality from them anyway. But one of the reasons, I moved here... [Because] I knew

there was a large lesbian population and it would be okay.”

Recommendations for disclosure

All participants said that if they were directly asked, they would disclose their sexual orientation. All participants responded that if “sexual orientation” was listed on an intake form, they would disclose, as exemplified in this participant’s statement: “If it were on a form, I wouldn’t have a problem with it [disclosing].” Participants also indicated they would disclose if “relationship status” included language for same sex relationships. One participant in a relationship said:

"I think they are way missing the point if it [a form] does not include a way to indicate same sex partnership whether it's by same sex marriage, civil union, or being in partnership with someone. Anything that does not include that, I find offensive.”

Another factor that participants indicated would encourage them to come out is the use of inclusive language and images in providers' marketing materials. One participant also described that a provider’s ability not to “flinch” when they verbalized their sexual orientation has made it easier to try it again with another provider. Another participant suggested that gay providers disclosing and being out in the community makes it safer and easier to disclose. One participant expressed that the provider’s staff be trained in order to reflect the provider’s leadership and acceptance of sexual orientation. One participant said,

“I think healthcare and social service providers need to be trained to not react. They have to be trained to treat everyone equally and sometimes you cannot train discrimination out of a person. Hospitals, medical offices need to be more aware of who they are hiring and almost like a jury selection and if this bothers you then you don’t get the job.”

Participants talked about the burden of having to disclose and to educate a provider on

sexual orientation. One participant said, “I would not volunteer it [disclose] if it is not related to my medical care. I don't know many single heterosexuals who have to say I'm heterosexual.” Another participant described why she always disclosed and why it is so frustrating when she explained:

"[We] use words and context that people can understand, they don't have a basis, so you have to drop back and go to their level. I don't always have the patience for it. It's tiring and monotonous... People [providers] that are homo-ignorant or heterosexist doesn't know what to ask, [they] leave you out... it's all that subtle stuff... They [providers] don't understand the health issues of being part of a minority... People have told me I don't have any discernment and I say no, I'd rather know where people stand, there is enough subterfuge and homophobia that people cloak in their own way where you never get told [openly] but you can feel it..."

Finally, participants talked about the importance of having the following documents:

- Healthcare proxy document (appoints someone to make your healthcare decisions if you can't);
- Living will (a document that directs a healthcare proxy or provider about medical decisions if a person becomes incapacitated);
- Advance directives (directs a healthcare proxy or provider under what circumstances to be kept alive if a person becomes incapacitated); and,
- Other legal documents to protect joint property or assets.

All of the coupled participants indicated that they were each other's healthcare proxies.

One single participant said, “I have chosen friends for my healthcare proxy that I know I can count on if I have too.” Other participant responses acknowledge the importance of the

documents to let providers know who they wanted to make decisions for them and what those decisions were. Not every participant stated whether they had documents in place. Four of the participants in relationships said they have used their durable power of attorney, healthcare proxy and in healthcare situations. One participant said, “I was adamant that I was her partner and that I was her healthcare proxy. We were out of state and we had our lawyer fax them [documents] right over. I think the staff was relieved that someone was there to make decisions.”

Summary

In general, the findings of this study found that the 17 participants did disclose their sexual orientation to providers and have had more positive experiences than negative with providers. However, every participant acknowledged the potential for discrimination and concomitant vulnerability, particularly in relation to long-term care. Discussions concerning the vulnerability of those seeking services in a nursing facility are reflected in the following two examples. One participant expressed her concern with the potential ramifications around sexual orientation documented in medical records, when she commented:

“I will not go back into the closet. They have to accept me the way I am. However, I have a legacy of dementia [in my family] so I feel especially vulnerable but hope that I can explain [my sexual orientation] to people. My concern is that we turn all our menial healthcare tasks over to a very conservative culture of people...I taught similar people and know the homophobia that I experienced...I tried to educate people...I wonder what will happen...maybe there should be a check box for the preference to not answer relationship, sexual orientation or gender identification.”

The second example involved a participant who described the possible vulnerability of being a gay male in a nursing home. He gave the example of an older straight man in a nursing

home saying something like, “Wow, she’s nice looking,” in referring to a woman he saw. A nurse or orderly would probably just pass it off. But if it were an older gay male who said it about a man, his fear was that he, as a gay man, might physically be harmed. The participant described the vulnerability as:

“I think we are at are most vulnerable [in a nursing facility], like infants, or puppies. I'm a little afraid of what will happen. There is a lot of old homophobia around the working class. My family was working class, I know. We [gay people] are very vulnerable. The idea that we are going to be there and can't move scares the shit out of me.”

Another participant related a story of two elderly gay men in their 80's that won't come out, even though they've been together for decades. One of them is in a nursing home.

So, in conclusion, while all participants said they would disclose to their primary care provider, findings indicate that for older LGBT adults there is still a perception of vulnerability in disclosing sexual orientation to health care and social service providers in general.

CHAPTER V

Discussion

Demographics

Demographic questions regarding age and sexual orientation were asked to qualify participants for the study. Additional demographics such as economics, education, ethnicity/race, geographic location, profession, religion and support systems were asked in order to describe the make up of the participants in the study. These questions were asked to ascertain if there was any association between demographic characteristics and decisions to come out to healthcare and social service providers. There were not any noteworthy associations between these quantitative data and the qualitative, thematic data concerning the experience of coming out. However, living in the gay friendly Pioneer Valley of Western Massachusetts was a common factor that everyone said contributed to their propensity to disclose their sexual orientation to healthcare and social service providers.

In addition to living in the gay friendly Pioneer Valley of Western Massachusetts, it is noteworthy that the 17 participants all demonstrated confidence and resiliency in relating their experiences of disclosing to providers. The demographics of the participants also indicate academic, professional and economic accomplishments that might be associated with confidence and self-assurance around coming out to providers. Each participant, whether coupled or single, was active in social or professional groups that could provide support in the face of everyday homophobia. All participants could identify at least one person as family or support, which is not always the case with every older LGBT adult. Research shows that 20% of LGBT single

older adults do not have an emergency contact as opposed to 2% of heterosexual adults; this can lead to higher degrees of loneliness and isolation in LGBT single older adults (Butler, 2006).

Disclosure

Even within this limited group of participants where everyone said they disclosed sexual orientation to some providers (or would if they were asked), the decision to disclose involved a process of assessing the particular provider for receptivity and safety. Some participants said they always disclosed. Most participants said they disclosed based on the relevancy of whether they thought the provider needed to know. Other participants said they felt out the situation before deciding. Coupled participants appeared to disclose more often because of their relationship and to assert their right to make healthcare decisions for each other.

These data may indicate that that it is more common and less stressful to disclose sexual orientation to providers in the gay friendly Pioneer Valley especially when the provider is known to be gay or lesbian or gay/lesbian friendly. However, it still was a topic that was not discussed lightly. All participants could personally remember a time when it wouldn't have been safe or acknowledged instances where it is still not safe for some older LGBT adults to disclose. Most participants acknowledged that there may be times in the future where they might not disclose and can understand why someone might choose not to disclose. Most participants acknowledged the privilege of their race, education, profession or geographic location as a factor in feeling more comfortable and being able to disclose.

There is a particular vulnerability whenever any LGBT person decides to come out. Similar to the data of Hitchcock and Wilson (1992), participants in this study have addressed this vulnerability around disclosure by:

- Deciding to disclose no matter what;

- Deciding to disclose based on relevancy;
- Feeling out the situation before disclosing;
- Finding providers by word of mouth; or
- Ascertaining that a provider is not gay friendly and choosing another provider.

There is potential for power and autonomy in the decision to disclose. LGBT older adults can use disclosure as a way of assessing a provider's reaction and to discern if there is any homophobia or if it is safe to be out. If a provider is homophobic or a situation is not safe, there is empowerment in choosing another provider in the future and spreading the word to others about what provider to avoid.

Managing disclosure allowed the study participants the ability to control who knows and who doesn't and when they want to share that information about themselves and prepare for a reaction. There can be a sense of control and mastery in making that decision. The data indicate that managing disclosure might help mitigate some of the stress of homophobic stigmatization and discrimination.

The anticipation, assessment and preparation in the disclosure process allow LGBT older adults the ability to assess how they may need to protect themselves. An additional benefit is that it helps LGBT older adults to share their health care or social service needs and concerns. The data indicate that, while the disclosure process may get easier each time one does it, disclosure always involves the potential for loss, specifically the loss of control over who knows about participants' sexual orientation. Participants discussed the potential for their loss of safety, both physically and emotionally. They suggested that even when society now perceives it as easier to disclose one's sexual minority status, the decision to come out is still a personally complex decision.

Implications for practice

The study data echoes the research from the literature that stresses the tremendous need for cultural competency education in LGBT aging issues for healthcare and social service providers. GLBT cultural competency trainings should be mandated by professional licensing agencies for all providers in the healthcare and social service fields.

The study finding that all participants did not feel the need to disclose their sexual orientation to all providers is worthy of discussion. Research has shown that there are higher rates of healthcare problems in LGBT older adults than in heterosexual older adults (Grant, et al., 2009). Studies also show that LGBT older adults experience better healthcare outcomes when they are out to their providers (Hudson, 2011). Outreach and education to the older LGBT adult population may make it easier for them to decide to disclose and thereby potentially contribute better healthcare and social service outcomes. However, based on the data from this study, it is important for professionals to respect individual concerns that may be based on the historical experience of severe discrimination and stigma in previous stages of life and in historical times when being out was more dangerous.

This study suggests that changes are needed in practice on the macro, mezzo and micro levels. On a macro level, healthcare and social service providers can advise and advocate for legislative mandates and social policies to include cultural competency education and trainings around LGBT aging issues. Healthcare and social service providers can advocate for the inclusion in the census of questions pertaining to sexual orientation and gender identification. Much more emphasis could be placed on research into LGBT aging issues, on legislation that protects older LGBT individuals from abuse and neglect, and on public health programs aimed at decreasing homophobic discrimination and increasing primary prevention for this population.

On a mezzo level, healthcare and social service providers could be more knowledgeable in LGBT aging issues and more available to support the family and social systems of the LGBT older adult. Healthcare and social service providers can create a professional environment that encourages safe disclosure and discourages discrimination.

On a micro level, healthcare and social service providers need to be aware of the legitimate fears and concerns of the aging LGBT population surrounding disclosure; they could support access to care and advocate for LGBT older adults individually. Healthcare and social service providers can help create a supportive environment for the growing older LGBT community so they can navigate through the complex process of aging in a predominantly homophobic, heterosexist society.

Healthcare and social service providers need to be able to recognize and appreciate the delicate process LGBT people face in letting providers know their sexual orientation or gender identification. Their roles as advocates can affect the ability of LGBT older adults to maintain their autonomy around disclosure and therefore empower them to decide who knows about their sexual orientation. On a very practical level, providers should be very judicious about the inclusion of information concerning sexual orientation in medical and social service records.

Implications for future research

The participants in this study were predominantly white, resilient, well educated and able to self-advocate. Participants also lived in an area that is perceived as gay friendly and disclosure appeared easier. It would be interesting to undertake future research exploring the topic of disclosure of sexual orientation or gender identification to healthcare or social service providers in different geographic areas that may or may not be gay friendly.

Future research would do well to extend recruitment outreach to underrepresented LGBT

older adults with more diverse ethnicity, race, age, academic and socioeconomic backgrounds, professional experiences, religions/spirituality and health status. Expanding recruitment beyond senior centers would be important.

Future qualitative research investigating the experience of LGBT older adults who are out to healthcare and social service providers and their satisfaction with outcomes would be useful to measure the effectiveness of disclosing. The data from this study suggest a need for research on the experiences of members of the LGBT older population who are out in health care or housing aggregate settings such as nursing homes, assisted living facilities and congregate housing facilities.

Limitation of this study

The limited response from recruitment was a limitation of the study. The venue of senior centers to recruit participants was not conducive to drawing a large enough sample. It would have been better to expand recruitment to other agencies that serve LGBT older adults. Participant inquiries only came from two out of the four senior centers plus the SAGE Western Massachusetts chapter. Twenty people responded, but only 17 were able to participate.

No bisexual or transgendered participants came forward for this study, therefore limiting the scope of this study. The stigma and discrimination that the transgendered population experiences might limit access to senior centers. Therefore, it would be important to recruit from organizations that support them. It may have been better to limit the study to one cohort (e.g. lesbians) and directly recruit within organizations that support or involve that individual cohort.

The researcher's own personal bias being a lesbian approaching midlife and living in the community where the participants resided may have influenced a participant's response. However, the researcher did not include individuals who were known to her personally, and she

made every effort to remain unbiased and to report the study findings objectively.

Finally, the geographic location of the study, the "gay-friendly" Pioneer Valley of Western Massachusetts, does seem to promote more ease with the disclosure of sexual orientation to healthcare and social service providers. While this limits the generalization of the findings, it also points out the benefits to older LGBT individuals living in regions, communities, and enclaves that are safe and supportive.

Conclusion

The findings from this study showed that participants in this study disclose their sexual orientation to healthcare and social service providers in the Pioneer Valley in Western Massachusetts. The findings also showed that participants considered the relevancy of disclosure before doing so. It is vitally important to older LGBT adults that they have power and control over who knows about their sexual orientation. They are accurately aware of how strong and virulent homophobia (the fear and hatred of gay people) can be, and they are understandably concerned about protecting themselves from it. Participants echoed this theme in their acknowledgement of their "privileged geographic position" and freedom to disclose. Their responses also indicated that, even with this privilege, coming out to health care and social service providers still reminds them of their vulnerability.

Some participants still expressed concerns about what could happen if they lose their ability to self-advocate and/or to control disclosure of their sexual orientation. Although this worry about the future was expressed by the sample, there was, surprisingly, little comment concerning the documentation of sexual orientation in provider records. This may reflect a lack of awareness of documentation concerns or it may reflect a lack of focus on this in the questions asked.

Some participants discussed their worry about what could happen to them if they were no longer able to take care of themselves. A survey conducted between 2009 and 2010 on long term care facilities confirms that LGBT older adults currently in facilities share their fear and that it is does not go unfounded. Out of the 769 people surveyed, 247 providers who worked in or with long term care facilities felt that LGBT older adults were not safe coming out or were not sure that they should come out. Seventy eight percent of LGBT older adults in long term care facilities responded that they could not or would not be open with facility staff, only 22% said they would. Forty three percent of respondents reported 853 instances of mistreatment, 93 respondents reported restrictions on visitors and 24 respondents reported denial of medical treatment. There were several recommendations as a result of the survey: more assessment and education in facilities, more involvement of ombudsman programs, social policy changes for funding of state and local communities to mandate cultural competency programs and conduct surveys and promote better health (National Senior Citizens Law Center, 2011).

By 2030, there will be 7.2 million older LGBT adults in need of health care and social services. There will be an increasing need for training related to LGBT aging issues. The National Resource Center on LGBT Aging provides LGBT cultural competency trainings. In 2006, the Joint Commission, which regulates assisted living and nursing care facilities, issued guidelines against anti-LGBT bias. However, they are not enforced, largely due to funding and because not all states have nondiscrimination language that includes sexual orientation (Grant, et al., 2009; McKenzie, 2010). If they were enforced, trainings could continue to be provided by the National Resource Center on LGBT Aging, Direct Care Alliance, Inc. or through the Administration on Aging in the Department of Health and Human Services.

The data from this study – narrative experiences of older gay and lesbian individuals in

coming out to health care and social service providers – underscore the resiliency and adaptation of a generation that has lived in a time of discrimination and marginalization based on sexual orientation. Through further research, cultural competency education and continued advocacy, healthcare and social service providers can support the resiliency of this generation of older LGBT adults and future LGBT generations to come.

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APPENDIX A
STUDY PARTICIPATION REQUEST

**Lesbian, Gay, Bisexual
and Transgender Older
Adults Wanted for
Study**



If you identify as lesbian, gay, bisexual or transgender (LGBT), are over the age of 55 and are willing to be interviewed for a study about coming out to healthcare or social service providers, please contact Mary Stanton at [removed] or at [removed].

Interviews will take about 1 hour. ALL INTERVIEWS WILL BE KEPT CONFIDENTIAL. There is no compensation for this study and participation is voluntary.

My name is Mary Stanton and I am a lesbian-identified Masters in Social Work (MSW) candidate at the Smith College School for Social Work. The data gathered through this study will support thesis research in this important and understudied topic.

In addition to participating or to support this research, please forward this invitation to anyone you know who meets the requirements for this study and may be interested.

APPENDIX B

Example of an Agency or Institution Approval Letter

AGENCY LETTERHEAD MIGHT BE PLACED HERE

DATE

Smith College School for Social Work

Lilly Hall

Northampton, MA 01063

To Whom It May Concern:

(Agency or Institution Name) gives permission for Mary Stanton to locate her research in this agency. We do not have a Human Subjects Review Board and, therefore, request that Smith College School for Social Work's (SSW) Human Subject Review Committee (HSR) perform a review of the research proposed by a Mary Stanton. **(Agency or Institution Name)** will abide by the standards related to the protection of all participants in the research approved by SSW HSR Committee.

Sincerely,

Signature

(Agency or Institution Director)

(Name of program, if applicable)

APPENDIX C

INFORMED CONSENT FORM

Dear Participant,

Thank you for your interest in participating in this study. This informed consent form details the purpose of this study, the involvement required and your rights as a participant. My name is Mary Stanton and I am a lesbian-identified Masters in Social Work (MSW) candidate at the Smith College School for Social Work. The purpose of this study is to explore LGBT older adults' decision to disclose or not disclose their sexual orientation or gender identification when seeking services from health care and social service providers. The data obtained in this study will be used for my MSW thesis and will hopefully add to the much needed research on LGBT aging and contribute to the overall quality of life for the LGBT older adults, their allies, families, friends and communities.

To participate in this study, you agree that you are at least 55 years of age or older and that you identify as either lesbian, gay, bisexual or transgendered. Your involvement will require that you participate in a one-to-one interview with me. You can choose whether to be interviewed by telephone or by an agreed upon public location that will ensure confidentiality. Interviews will be recorded to accurately capture your responses.

Minimal risk from participation is anticipated. However, discussions around the disclosure of sexual orientation or gender identification may bring up uncomfortable feelings or questions about the stigmatization or discrimination a participant may have experienced as a member the LGBT community. A list of LGBT supportive resources are listed at the end of this document. The interview will take approximately 60 minutes. At any time, you may decline any question that is asked. At any time, you can end the interview and end involvement in the study.

You will be assured of confidentiality and anonymity. The recordings will only be heard by me and a transcriber who signed a confidentiality agreement. A research advisor will have access to data obtained from recordings but no identifying information of the participants. In accordance with federal guidelines, data will remain securely stored for a period of three years, after this period, the data will be destroyed or continue to be maintained securely. Data will be discussed in the aggregate to protect the confidentiality of participants. Any interview excerpts quoted in the findings will be carefully disguised to remove any potentially identifying information.

Participation in this study is voluntary. No compensation will be given for participation. You may withdraw from the study at any time until April 27, 2012 by contacting me by phone at [removed] and if you do so, all the data from your interview will be immediately removed and destroyed. If you have any with questions or concerns about your rights or this study you may contact me at the contact information listed below or the Chair of the Smith College School Social Work Human Subjects Review Committee at (413) 585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

(SIGNATURE)

(DATE)

Researcher's Contact Information:

Mary M. Stanton
School for Social Work
Lilly Hall
Smith College
Northampton, MA 01063
Phone: [removed]
email: [removed]

LIST OF RESOURCES FOR OLDER LGBT ADULTS

Local Resource for LGBT Aging:

J.M. Sorrell, Director, SAGE Western Massachusetts
320 Riverside Drive, Suite B Northampton, MA 01062
Phone: (413) 586-2000, extension 146
Email: jmsorrell@sagewm.org
Website: <http://www.sagewm.org>

SAGE Western Massachusetts offers monthly educational series and social gatherings at the Northampton Senior Center the last Wednesday of every month from 1 to 3 p.m. and at the Bangs Community Center in Amherst the first Thursday of every month.

LGBT Aging Project

555 Amory Street
Boston, MA 02130
Phone: (617) 522-6700
Email: info@lgbtagingproject.org
Website: www.lgbtagingproject.org

National Resource Center on LGBT Aging

c/o Services & Advocacy for GLBT Elders (SAGE)

305 Seventh Avenue, 6th Floor

New York, NY 10001

Phone: (212) 741-2247

Email: info@lgbtagingcenter.org

Website: <http://www.lgbtagingcenter.org/resources/>

APPENDIX D

INTERVIEW QUESTIONS

DEMOGRAPHIC QUESTIONS

Initial Screening Demographic Questions:

Age:

What year were you born?

Sexual Orientation:

What is your sexual orientation?

Gender:

What is your gender? Do you identify as transgender?

Interview Demographic Questions:

Disability status:

Do you have a disability? Do you consider yourself disabled or living with a disability?

Education:

What is the highest degree or year of school you have completed?

Employment Status:

What is your employment status?

Employer Type:

What best describes/described your profession?

Ethnicity/Race:

How do you identify yourself ethnically and racially?

Family/Support System:

Who in your family or broader social network do you turn to for support?

Age of Sexual Orientation Identification:

At what age did you realize that your sexual orientation was other than heterosexual?

Geographic Location:

Which community do you reside in? Amherst, Easthampton, Hadley, Northampton or Other

Housing Arrangement:

Do you rent or own a house, condominium, apartment, mobile home or other?

Do you live alone? If you do not live alone, with whom do you live with?

Household Income:

What range does your total annual household income fall within?

Under \$20,000

\$21,000 to \$40,000

\$41,000 to \$69,999

\$70,000 to \$89,000

Over \$90,000

Relationship Status:

What is your relationship status?

Religious or Spiritual Affiliation

Do you have a religious or spiritual affiliation?

Veteran Status:

Are you a veteran?

GENERAL OPEN-ENDED INTERVIEW QUESTIONS –

1. When is the first time you had romantic feelings for another of the same sex or if transgendered, felt that you were a different sex than your sex assigned at birth?
2. When did you first acknowledge your LGBT status to another person?
3. What are the factors that influence whether you come out or not with healthcare providers or social service providers?
4. What experiences have you had with the decision to come out or to not come out with healthcare providers or social service providers?
5. Do you have any concerns regarding documentation of your sexual orientation or gender identification with healthcare providers or social service providers? If so, what are they?
6. What factors do you think would help to make the decision to disclose sexual orientation or gender identification with healthcare providers or social service providers easier?

APPENDIX E

HUMAN SUBJECTS REVIEW APPROVAL LETTER



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

March 14, 2012

Mary Stanton

Dear Mary,

What a great job! I look forward to hearing what you have found. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Best of luck on this interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'David L. Burton', with a horizontal line underneath.

David L. Burton, M.S.W., Ph.D.
Chair, Human Subjects Review Committee

CC: Bruce Thompson, Research Advisor

APPENDIX F

RESEARCH CONFIDENTIALITY PLEDGE for Interview Transcriber

This thesis project is firmly committed to the principle that research confidentiality must be protected and to all of the ethics, values, and practical requirements for participant protection laid down by federal guidelines and by the Smith College School for Social Work Human Subjects Review Committee. In the service of this commitment:

- All volunteer and professional transcribers for this project shall sign this assurance of confidentiality.
- A volunteer, or professional transcriber should be aware that the identity of participants in research studies is confidential information, as are identifying information about participants and individual responses to questions. The organizations participating in the study, the geographical location of the study, the method of participant recruitment, the subject matter of the study, and the hypotheses being tested are also be confidential information. Specific research findings and conclusions are also usually confidential until they have been published or presented in public.
- The researcher for this project, Mary M. Stanton shall be responsible for ensuring that all volunteer or professional transcribers handling data are instructed on procedures for keeping the data secure and maintaining all of the information in and about the study in confidence, and that that they have signed this pledge. At the end of the project, all materials shall be returned to the investigator for secure storage in accordance with federal guidelines.

PLEDGE

I hereby certify that I will maintain the confidentiality of all of the information from all studies with which I have involvement. I will not discuss, disclose, disseminate, or provide access to such information, except directly to the researcher, Mary M. Stanton for this project. I understand that violation of this pledge is sufficient grounds for disciplinary action, including termination of professional or volunteer services with the project, and may make me subject to criminal or civil penalties. I give my personal pledge that I shall abide by this assurance of confidentiality.

Signature

Date

Mary M. Stanton

Date